# When should you involve patients in treatment decisions?

Three papers in this issue of *BJGP* call on doctors to adapt their practice styles to encourage more active patient engagement. Greaves and Campbell make a strong case for supporting self-care, while Bryant *et al*<sup>2</sup> and Cox *et al*<sup>3</sup> tackle the issue of how to involve patients in treatment decisions. There is an ethical, political, and scientific basis for moving in this direction, but the practical implications are complex.

There is much evidence that engaging patients in treatment decisions and supporting their efforts at self-care can lead to beneficial outcomes.4,5 Patients who are active participants in a shared decision-making process have a better knowledge of treatment options and more realistic perceptions of likely treatment effects. The resulting treatment choices are more likely to concur with their preferences and attitudes to risk.6 Actively engaged patients are also more likely to adhere to treatment recommendations, and less likely to select expensive procedures.7,8 However, patients' desire to play an active role in decision making varies, and, according to Cox et al, GPs are not very good at predicting what role patients want to play.3 What should be done about this problem?

Two possible solutions present themselves: asking patients explicitly whether they want to be involved in deciding how to manage their condition and adapting your decision-making style accordingly; or ignoring patients' initial inclinations and actively encouraging them to get involved because it's good for them to do so.

When choosing a treatment or preventive procedure, the aim is to select options that increase the likelihood of desired health outcomes and minimise the chance of undesired consequences. Since there are often multiple options for treating a problem and the benefit/harm ratios are frequently uncertain or marginal, the best choice depends on how an individual patient values the potential benefits and harms of the alternatives.

The desire for participation has been found to vary according educational status, disease severity, nationality, and ethnic origin, but these factors explain only part of the variance in individual preferences.4 None of these observable characteristics is a reliable predictor of what the individual patient wants. The only reliable way to find out patients' preferred role is to ask them directly, but their responses may be influenced by previous experience. Some patients may assume a passive role because thev have never been encouraged to participate and remain unaware of the potential for doing so. Others may simply feel it is impolite to imply that the doctor doesn't necessarily know best.

For true shared decision making to take place patients must be given sufficient and appropriate information, including detailed explanations about their condition, treatment options, outcomes, uncertainties. The doctor must have the scientific facts at his or her fingertips, must be skilled in risk communication, and must check that the patient has understood the information and can assess its implications. A number of evidence-based patient decision aids have been developed to assist in this process (http://decisionaid.ohri.ca/). However, this can be quite a lot to take and some patients may prefer not to receive this information or find it difficult to absorb and understand.

It is tempting to conclude that the information-giving process could be short-circuited if you could determine at the outset that the patient didn't want to be involved in the decision. The problem is that it doesn't make much sense to ask patients to indicate their preferred role in decision making before they have been informed about the nature of the choices they face. Also, many patients do want extensive information and a chance to express their preferences, even if they decide to delegate decision making to the doctor.

Currently, many patients expect to be actively involved in all decisions that affect them, but the evidence suggests that shared decision making is not the norm. 9,10 Doctors often fail to explore patients' values and preferences and there are significant gaps between patients' desire for involvement and their experiences. In a national survey of general practice patients' experience carried out in England in 2006, 42% of responders said they would have liked more information about medicine side effects and 45% indicated that they had not had sufficient involvement in choosing their medication. 11

Clinicians in the UK appear to be more reluctant to give their patients a say in treatment decisions than those in other developed countries. This may be because they judge that their patients do not welcome it, but deference to professional authority is rapidly giving way to a desire for a more equal relationship and it is important that practice keeps up with, and indeed embraces, these changed expectations.

There is considerable debate about when, and to what extent, patients should be actively encouraged to participate in treatment decisions. Many advocates of shared decision making suggest it should be restricted to preference-sensitive decisions, that is, those where it is generally agreed that the patient's values should guide the choice. Examples include choice of contraceptive method; hormone replacement therapy to control menopausal symptoms; mastectomy versus lumpectomy for breast cancer; and surgery, drug therapy or watchful waiting for menorrhagia or benign prostatic hypertrophy. This school of thought sees shared decision making as the best approach in situations of uncertainty when two or more clinically reasonable alternatives exist. But even in these cases, some would argue, if patients have indicated that they prefer the doctor to make the decision this must be respected.

Others have suggested that obtaining

informed consent requires doctors to give patients full information in all cases of significant risk, even if there is only one treatment possibility. After all, there is still a decision to be made because the patient has to choose between two courses of action: to accept or reject the treatment. McNutt argued that doctors should never make choices for patients; instead, they should play the role of navigator, communicating risk and outcome probabilities and helping patients to make informed decisions for themselves.

The latest version of *Good Medical Practice* says doctors should listen to patients and respect their preferences, give patients the information they want or need in a way they can understand, and respect patients' right to reach decisions with the doctor about their treatment and care. <sup>14</sup> This does not imply you should force patients to take responsibility for decision making against their will, but it does suggest that you should make serious efforts to provide information about the treatment or management options, explain it, elicit their preferences,

and support them in weighing up the alternatives unless they tell you they don't want to be involved. How far you should go in persuading them to play an active role if they are hesitant about doing so, must remain a matter for debate.

#### **Angela Coulter**

Chief Executive, Picker Institute Europe, Oxford.

#### REFERENCES

- 1. Greaves CJ, Campbell JL. Supporting self-care in general practice. *Br J Gen Pract* 2007; **57(543):** 814–821.
- 2. Bryant LD, Bown N, Bekker HL, House A. The lure of 'patient choice'. Br J Gen Pract 2007; 57(543): 822–826.
- Cox K, Britten N, Hooper R, White P. Patients' involvement in decisions about medicines: GPs' perceptions of their preferences. Br J Gen Pract 2007; 57(543): 777–784.
- Coulter A, Ellins J. Patient-focused interventions: a review of the evidence. London: The Health Foundation, 2006
- Coulter A, Ellins J. Effectiveness of strategies for informing, educating and involving patients. BMJ 2007; 335: 24–27.
- O'Connor AM, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2003; 1: CD001431.
- Stevenson FA, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expect* 2004;

- 7(3): 235-245.
- Kennedy ADM, Sculpher MJ, Coulter A, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs. JAMA 2002; 288: 2701–2708.
- Britten N, Stevenson FA, Barry CA, et al. Misunderstandings in prescribing decisions in general practice: qualitative study. BMJ 2000; 320(7233): 484–488.
- Stevenson FA, Barry CA, Britten N, et al. Doctor-patient communication about drugs: the evidence for shared decision making. Soc Sci Med 2000; 50(6): 829–840.
- 11. Picker Institute Europe. *National survey of local health services 2006*. London: Department of Health, 2007.
- Coulter A. Engaging patients in their healthcare: how is the UK doing relative to other countries? Oxford: Picker Institute Europe, 2006.
- 13. McNutt RA. Shared medical decision making: problems, process, progress. *JAMA* 2004; **292(20)**: 2518
- General Medical Council. Good medical practice. London: GMC, 2006.

#### ADDRESS FOR CORRESPONDENCE

#### **Angela Coulter**

Picker Institute Europe, King's Mead House, Oxpens Road, Oxford OX1 1RX. E-mail: angela.coulter@pickereurope.ac.uk

## **Antimicrobial resistance:**

### increasing concerns

Were Charles Darwin alive today he would rapidly understand many of the issues surrounding antimicrobial resistance. They represent 'survival of the fittest' at their most dynamic. Darwin drew upon examples from the Galapagos (finches and tortoises), as well as fossil records, and realised that evolution had occurred over millennia (at the least). This brought him into conflict with conservative elements in the church (with the argument still rumbling on today in the Creationist versus Evolutionist debate).

In the interaction between pathogen and antimicrobial, evolution occurs over a very short period of time. As is well known, remarkably soon after the introduction of penicillin, staphylococcal

and now resistance was reported 90% resistance rates exceed in Staphylococcus aureus. Similarly, staphylococcal resistance fluoroquinolones was reported during the pre-marketing clinical trials1 and has continued to rise.

The reasons for this telescoping of time are not difficult to understand. The selection of a genetic characteristic depends upon the interplay of a number of variables. While the Galapagos tortoises were relatively few, vast numbers of bacteria are in the gastrointestinal tract and on the skin, say 10<sup>11</sup> or 10<sup>12</sup>. Secondly, many bacteria can reproduce, double in number in 20 minutes, although the tortoise generates only few offspring in a

long life. Finally, bacteria have a variety of means of passing genetic information to future generations in addition to simple division; these include conjugation (where bacteria exchange DNA via contact), bacteriophage transduction, and the direct uptake of DNA (transformation). Only the sexual method is available to tortoises. Add to this a very potent selection pressure, an antimicrobial, and resistance will readily emerge in bacteria.

For example, it is possible to select for fluoroquinolone resistance *in vitro* by overnight exposure of a *Staphylococcus* or *Escherichia coli* to the compound. These laboratory experiments may not represent the *in vivo* conditions, but they do underline just how readily resistance